State of the State

The Missouri Planning Council for Developmental Disabilities is proud to present this State-of-the-State Report describing the needs of Missourians with disabilities and their families, the services and supports that they currently access, a comparison of Missouri to other states, and, most importantly, the Council's recommendations on steps that Missouri should take in order to develop a system that meets the Council's mission of community inclusion for all people with developmental disabilities in every aspect of life.

In order to develop a strategic plan that would drive the Council's activities and projects over the next five years, the Council embarked upon a two-year effort to conduct a statewide needs assessment and to review and analyze the services and supports available to Missourians with developmental disabilities. With the assistance of the University of Missouri, Kansas City, Institute for Human Development and the Developmental Disabilities Regional Advisory Councils, information was gathered from 127 focus groups held in 110 of Missouri's 114 counties. Nearly 1,000 individuals participated in the focus groups with 41 percent being individuals with developmental disabilities and 59 percent family members of individuals with developmental disabilities. Sixty-four percent of the focus group participants received services and 36 percent received no services or service coordination only. Additional information was also obtained from 737 respondents to a written survey, the majority (64 percent) of these respondents were family members.

This project addresses major areas of concern to people with developmental disabilities including employment; residential settings; transportation; childcare and early intervention; education; health care; recreation and social opportunities; community resources and support issues; safety and quality assurance, and satisfaction with services. Please take some time to review our findings and recommendations and join us in bringing systems change to Missouri that provides the services and supports needed so that all of Missouri's citizens can be a part of their community and enjoy the same rights and privileges as all other citizens.

Sincerely,

Terry Mackey, Chairperson

- State of the State -- Childcare
- State of the State -- Community Resources

- State of the State -- Early Intervention
- State of the State -- Education
- State of the State -- Employment
- State of the State -- Health
- State of the State -- Housing
- State of the State -- Recreation
- State of the State -- Safety & Quality Assurance
- State of the State -- Transportation

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The State of the State for Missourians with Disabilities

CHILD CARE

"When the child care system fails, everyone suffers. Children receive substandard care, the field is plagued by high turnover, workplace productivity is sapped and children enter our schools not fully prepared to succeed. Society misses an opportunity to prepare children for the future at the time they are most ready to learn. We can do a better job of caring for our youngest citizens."[1]

Our Beliefs

The mission of the Missouri Planning Council for Developmental Disabilities (MPC) is to "*assist communities in their efforts to include all people in every aspect of life*." The council believes in the importance of individual and family supports which are flexible, based on need, and provided in a culturally sensitive manner. The MPC supports the federal outcome that children and families benefit from a range of inclusive and flexible child care options. MPC has supported, and continues to support the goal of increasing the number of providers of inclusive early child care and education and the number of children with special needs who are supported within inclusive child care.[3]

> ***"Early childhood care and education begins at birth. It can have either a positive or negative effect on children and their long-term development. The state of Missouri will assure the provision of quality early childhood care and education that promotes positive results for all its residents."***
>
> **Committee on Early Childhood Care and Education appointed by former Governor Mel Carnahan (1997)[2]**

What the Research Says

Under the Americans with Disabilities Act (ADA) of 1990, child care centers are considered to be a public accommodation and may not discriminate on the basis of disability. Reasonable modifications to policies, practices and procedures must be made in order to accommodate special needs of children with disabilities and special healthcare needs.[5] *Because the child care setting may be the first environment in which a child's disability is identified, it is critical that child care programs have the knowledge and skills to serve children with special needs.*

Although the ADA prohibits discrimination based upon disability, many parents of children with special needs face difficulties when seeking child care. One barrier to accessing inclusive child care is that some daycare providers are unwilling to accept a child with a disability because of the need for specialized care or because providers have no experience in caring for children with disabilities. Another barrier is the lack of parental knowledge of services and systems in terms of available programs and legal rights.[6]

Since 1990, the Child Care Development Block Grant (CCDBG) has been the primary source of child care funding to the states from the federal government.[7] However, only 14% of urban accredited child care centers, and 4% of rural accredited centers accept subsidy funds.[8] Research by the National Women's Law Center indicates that without additional funding, in the midst of rising poverty rates, approximately 400,000 children are expected to lose child care assistance by 2011, in addition to the estimated 250,000 children who have already lost assistance since 2000.[9]

One study, which examined a cross-section of eight cities in the nation, found that child care was consistently the largest monthly expense for families, at times costing twice the average housing expense.[10] For many families, especially lower-income families, such costs are simply unaffordable.[11] Single parents are especially hard-hit by child care expenses, a consideration in light of the high divorce rate for families with special needs children.

What Missourians with DD and Their Families Are Saying[4]

Statewide Needs Assessment Results

Child Care Choices
Respondents thought families of children with disabilities were *most likely* to use:
(70%) care provided by family/friends
Respondents thought families of children with disabilities were *least likely* to use:
(49%) regular child care
(41%) segregated or special child care

Adequacy of Child Care Options
(78%) segregated child care rated inadequate/fair
(73%) regular child care rated inadequate/fair
(69%) friends/family rated good/excellent

Opportunities for Community-Based Child Care
(75%) inadequate/fair
(26%) good/excellent

Challenges in Child Care for Children with Disabilities:
- **Lack of options**
- **Systems limitations (i.e., age caps on children)**
- **Lack of available family/friends to provide child care**
- **Lack of care during alternative work hours (night shift)**
- **Need for quality, licensed providers**
- **High turnover at daycare**

"There is no child care within our area that will accept special needs children."

"It's sad when you can't work because you can't find child care."

Roux, A. & Radicia, C., 2007

The State of the State in Child Care

Child care helps our economy today by making it possible for parents to work and helps the economy of tomorrow by preparing our future workforce.[12] A survey in Minnesota revealed that a significantly higher number of parents of children with special needs reported child care problems that interfered with their ability to accept or keep a job during 2004, as opposed to parents whose children did not have special needs.[13] Missouri families often find that locating early learning programs that meet their needs is difficult, and these same problems are particularly pronounced for families with children with special needs.[14]

Currently, there is insufficient data regarding inclusive child care in Missouri. In a survey of child care providers within Midwestern states, only 1/3 of providers reported including one or more children with a disability in their program. Children with disabilities were enrolled in ½ of the center-based programs and merely ¼ of the family homes.[15] Unfortunately, these numbers leave the majority of children with special needs under-served and left with few options. It is, therefore, no surprise that opportunities for community-based childcare were rated as *inadequate or fair* by 75% of Needs Assessment respondents.[16]

> ***"When children reach age 12 they can't go to regular child care. Providers can apply for a waiver but there are no incentives for the provider."***[17]

Finding adequate child care for children with special needs is a particular challenge within rural areas of Missouri. 42% of Missouri's children lived in rural areas in 2005.[18] Yet, the supply of center-based early childhood programs, as well as after-school programs, is lowest within the rural area of Missouri.[19]

In order for parents of children with disabilities to work, childcare must be available, accessible, and affordable. Statistics show that a middle-income Missouri family of four with an infant and preschooler in care could spend between 18% and 32% of its annual income on child care.[20] To have two children in daycare costs more than Missouri public college tuition.

MO Avg Annual Out-of-Pocket Expenses to Families 2004[21]

Child Care – 1 Child, Full-time	$3,910	15-18% of Total Income
Child Care – 2 Children, Full-time	$7,820	-
Public College Tuition	$5,858	5-7% of Total Income

Source: Missouri Child Care Resource and Referral Network

Missouri's income cutoff for qualification for child care assistance has now fallen to the lowest in the nation. A family of three in Missouri now has to make below $18,216 per year, 110% of the federal poverty level, in order to qualify for child care subsidies.[22] In 2005, the earnings of a single parent working full-time at minimum wage covered just 40% of the estimated cost of raising two children.[23] It is important to note that a Minnesota study indicated that households with low incomes are more likely than households with higher incomes to have a child with special needs (13% versus 5%).[24]

What We Recommend

Many of the recommendations below are repeated within many recent studies that outline specific areas of improvement. They are intended to enhance the basic assurances for inclusion of children with disabilities within community settings already provided within the ADA and Individuals with Disabilities Education Improvement Act (IDEA 2004) laws.

- A comprehensive assessment of the state of child care for children with disabilities in Missouri to identify:
  - Accurate measures of the current need for inclusive child care across age groups.
  - Evaluation of current capacity of all child care settings to provide for children with disabilities.
  - Barriers to the development of further capacity for inclusion in Missouri, from the perspective of providers, including a review of regulations and statutes, the infrastructure and processes for coordination of services, and collaboration among providers.
  - Barriers to the use of child care from a parent perspective.
- Increase education of child care providers and parents regarding the rights and requirements of the ADA that relate to the provision of quality child care.
- Efforts to expand the use of existing Quality Rating System tools in conjunction with technical assistance to support quality improvement should be an area of focus, while developing quality measures specific to inclusive care practices.
- Expand competency based training regarding inclusion should be provided to child care providers in conjunction with other required trainings, to support consistency of provided information. Follow-up, hands-on training is often valuable in addressing needs of children with complex needs and challenging behaviors.
- As the Missouri Governor's Coordinating Board for Early Childhood considers financing, as well as the state of Missouri's children, increases in eligibility cut-offs for child care subsidies should be strongly considered.
- Differential subsidy reimbursement rates should be considered, with higher-quality child care receiving higher reimbursement. This would act as a dual incentive for programs to raise their quality level, and for programs with higher quality to accept child care subsidies.

- A liaison should be established to advise the Department of Mental Health representative to the Missouri Governor's Coordinating Board for Early Childhood regarding child care needs of children with developmental disabilities from the perspective of the MPC.

CHILD CARE ENDNOTES

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COMMUNITY RESOURCES AND SUPPORTS

"It is NOT reasonable to deny even one person the right to live among us in the community, where services and supports can be provided."[1]

Our Beliefs

A principle belief of the Missouri Planning Council for Developmental Disabilities (MPC) is that all people with developmental disabilities (DD) belong in their community. In order to achieve community inclusion, people with DD and their families should be informed, active and equal partners in policymaking.[2]

MPC Beliefs

- ***People with DD are supported in their communities near families and friends.***
- ***Community based services and supports promote a positive image and awareness of people with DD.***
- ***Community based services and supports provide opportunities for people with DD to be valued members of the community, making contributions as well as receiving needed supports.***
- ***The system should promote the use of community resources, and, in so doing, build community capacity.***

What the Research Says

When the role of the case manager was created in the 1970's, this person was intended to be a powerful monitor, advocate, and service coordinator for people with DD. However, modern case managers are limited in being able to fulfill this role, not because they don't want to, but because the evolving demands of their jobs do not allow them to do so. These new roles ask case managers to change the balance of power and control, and turn the decision-making authority over to the consumer and their family.[3]

Modern case managers are also required to provide information about resources to assist persons with DD through the system as they age, a job that is critical due to the current limited resources. In the age of the internet, demand for easily accessible online resources is constantly increasing.

The State of the State in Community Resources and Supports

Within the top five strategies the Needs Assessment participants listed for bettering communities for persons with DD was the need for more information and resources for persons with DD and families.[5]

MODDRC. The Missouri Developmental Disability Resource Center provides information, peer support, and volunteer leadership opportunities for Missourians with disabilities, their families, and for community providers. Peer mentorship is provided by connecting parents, self-advocates, and professionals throughout the state with "matches" for ongoing and immediate support, via the Sharing Our Strengths (SOS) program. This program has shown a 14% increase from 2005 to 2006 in requested support matches.[6]

Several of the organizations in the state that provided lending libraries of information about DD have ceased lending materials. It appears that only two sizable, online lending libraries now remain—MODDRC servicing the entire state, and Special School District of St. Louis County Family and Community Resource Center (SSD FCRC) servicing St. Louis County.

MODDRC reported 872 requests for information from persons across the state in FY2006, a 5% decrease from the 921 requests in FY2005.[8] In comparison, the SSD FCRC, servicing one county, reported a total of 2,819 contacts for 2006, a 40% increase over 2005. Increases were attributed to planned outreach activities, including a comprehensive, systematic distribution system; email communication; and targeted outreach to underserved areas.[9]

"They need to find a way to unite families to share information with each other."[7]

Public Awareness. MPC provides partial funding for Regional DD Advisory Councils across the state. These councils are knowledgeable about local needs and service gaps in their region and provide a

What Missourians with DD and Their Families Are Saying[4]

Statewide Needs Assessment Results

When asked to rate resources and supports provided by civic organizations, faith-based organizations, social service organizations, and family/friends:

Respondents thought people with DD were *most likely* to use:
- **Family/friends (61%)**

Respondents thought people with DD were *least likely* to use:
- **Civic organizations (60%)**

Adequacy of Options
(76%) Civic organizations rated inadequate/fair
(60%) Social service organizations rated inadequate/fair
(77%) Family/friends rated good/excellent
(57%) Faith-based organizations rated good/excellent

How supportive are communities?
(40%) Somewhat supportive
(56%) Not supportive or only somewhat supportive

Participants clearly indicated that increased services and supports, beyond that covered by Medicaid, were necessary to attain an improved quality of life.

grassroots planning and advocacy for improvements in supports and services for persons with DD. The Regional Councils are also the main advisory group to each of the Division of Mental Retardation and Developmental Disabilities' (MRDD) eleven regional centers. The authors of *Show Me Change* (1998) noted the need for Regional Councils to become accountable for incorporating person-centered principles and recommended the Regional Councils communicate with Regional Centers to infuse those principles into the provision of supports and services. This appears to still be a need today.[10] One of the top concerns identified in the Needs Assessment final participant comments[11] was the need for increased community understanding of DD in order to address attitudes and perceptions. For example, it is difficult for the general public to understand transportation issues that are unique to persons with disabilities. Education is needed in order for the general public to understand the importance of accessible transportation that is available when people with disabilities need it.

The need for public awareness takes two forms:

1) Education of self-advocates and families on topics of importance, in order to create informed leaders that can effectively increase community awareness**;** and, **2)** Education of the public regarding the need for opportunities for persons with DD to participate in community activities, recreation, employment, housing, and so forth.

Regional Centers. The 11 regional centers in the state are the entry and exit point for consumers. The centers provide screening and diagnostic services for both children and adults, evaluate the need for services and arrange for them, and assess consumers' progress.

Although families and providers were generally satisfied with Service Coordination (SC) according to the Needs Assessment, they both noted inconsistencies in quality across Service Coordinators (SCs) with no built-in opportunities for providing feedback.[12] According to a recent report, large caseloads are the norm for SCs and workers report high levels of stress and general job dissatisfaction. Staff also report too many job responsibilities and paperwork burdens. These factors contribute to a perceived shift away from person-centered care due to limited time to focus on the "consumer".[13]

A frequently noted concern was the "wait lists" for MR/DD services through the Regional Centers, which are viewed as a direct result of inadequate funding.[14] Concerns voiced in a recent Regional Center review regarding waiting lists centered around the fear that the Department of Mental Health (DMH) and MRDD have become a Medicaid-only system.

"—if an individual is not eligible for Medicaid, that person will not receive services and may languish on the waiting list. It was stated frequently that individuals and families on the waiting list must go into crisis and then services may be approved. There was a great deal of frustration expressed about this, explaining that some temporary or interim type of service might avoid a crisis and the ensuing disruptions for families and consumers."[15]

Senate Bill 40 Boards. The Senate Bill 40 Boards (SB40) or "County Boards" were formed to distribute special tax levies, or "mill" taxes, that were passed by county residents to benefit people with DD. These taxes have historically been used to support, care for, or provide employment, transportation, or residential living of persons with DD. Over 80 counties in Missouri and St. Louis City currently have this tax in place. 93% of persons with DD in Missouri live in counties serviced by SB 40 boards; 7% (or 7,100) of the estimated 101,000 Missourians with DD in 2003, do not have a SB 40 board in their county.[16]

"There are no apartments or anything in Stone County. Other counties have them because they live in counties with SB 40 Boards."[17]

Senate Bill 40 funds are viewed as a potential source for improving such services as person-centered planning and implementing pilot programs. However, concerns in recent testimony were noted regarding: 1) disparities in SB 40 boards and the services they offer across various regions of the state; 2) need for better oversight and accountability of county usage of SB 40 funds.[18]

What We Recommend

It is now well known that simply placing persons in the community does not automatically equate to acceptance by the community, inclusion in the community, and improvements in quality of life. The following recommendations support needed improvements in community resources.

- Promote self-direction of services for individuals with DD as the primary way that services are managed and delivered in Missouri. Increase availability of self-directed services and provide education and training regarding these options for policy makers, self-advocates, families and the provider community.
- Encourage efforts that lead to all services and supports that individuals with DD receive, maintain, or increase community inclusion.
- Decrease services coordination caseload size to a 1-50 ratio to ensure quality service delivery.

- Support efforts to raise the level of respect of direct care staff and use the College of Direct Support to meet the needs for ongoing training and credentialing as well as to improve recruitment, retention, and compensation for direct care staff.
- Support and advocate for the DMH's budget requests for community based services in order to increase funding and meet the needs of individual and families on the MRDD waiting lists.

COMMUNITY RESOURCES AND SUPPORTS ENDNOTES

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EARLY INTERVENTION

"While children with disabilities may have very different needs, including significant medical needs, our goal should be to ensure our children live natural lives, included in their homes and communities, from the earliest possible moment. Unfortunately, the special programs and services many parents have come to depend on force children to live unnatural lives, isolated and segregated from the mainstream of their communities."[1]

Our Beliefs

The Missouri Planning Council for Developmental Disabilities' (MPC) mission is to assist the community to include all people with developmental disabilities (DD) in every aspect of life. In regard to education, the council believes this mission will be achieved when people with DD attend school with their peers in regular classrooms and neighborhood schools. [2]

MPCDD Goal

Students and young children receive quality education in inclusive settings.

What the Research Says

Early intervention services for infants and toddlers, and early childhood special education services for preschoolers are made available through a federal law known as the Individuals with Disabilities Education Improvement Act of 2004. The federal law is based in principles of early intervention and requires systems to: 1) center on families; 2) maximize the participation of children and families in natural environments; 3) foster interactions with children without disabilities; and 4) integrate and coordinate activities at all levels of the system.[3]

In regard to the current state of early intervention in this country, "…universal access to inclusion is far from a reality, practices differ radically from community to community without any apparent rationale, and controversy is common across states with respect to how to interpret and apply the concept of natural environments."[4] Each of these dilemmas is certainly true in Missouri.

The long-term economic benefits of high-quality child care have been well documented[5], with government earning an $8 return for every dollar invested in early intervention.[6] Benefit-to-cost ratios such as these are in stark contrast to the less robust returns of other investments made by government.[7] Given the high rate of return to investment in early childhood education at every age, logic dictates that when making budget decisions, policy makers should look to other state expenditures with lower rates of return rather than making trade-offs within early childhood care and education budgets.[8]

The State of the State in Early Intervention

In Missouri intervention for children with DD ages 0-2 is delivered via the First Steps (FS) program and through school district early childhood special education (ECSE) programs for ages 3-5. The chart below details the children served in Missouri over the last several years.[10]

CHILD COUNTS	2000	2001	2002	2003	2004	2005	2006
First Steps 0-2 years	3,039	2,825	2,942	3,423	3,445	3,188	3,350
ECSE 3-5 years	8,036	9,007	10,049	10,893	10,856	10,898	(na)
Public Preschool	(na)	4,400	10,697	11,604	14,169	17,849	(na)

(na) = data not available

First Steps. Missouri's participation in the First Steps program is a voluntary, but vital, choice for the children of our state. The program seeks to fulfill the federal policy on early intervention "to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system that provides early intervention services for infants and toddlers with disabilities and their families.[11] Yet, **Missouri only ranks 45th nationally** in the percentage of children served to age three, at 1.53%, according to federal special education data. This compares to the national average of 2.51% of children served.[12]

A 2006 state audit of Missouri First Steps found that children's access to the program was being limited by establishing eligibility criteria more restrictive than most states. According to department officials, the eligibility criteria have remained restrictive for budgetary reasons, focusing on serving more severely disabled children. While states with broad eligibility criteria for entry into early intervention find

***What Missourians with DD and Their Families Are Saying*[9]**

Statewide Needs Assessment Results

Respondents thought families of children with disabilities were *most likely* to utilize Early Intervention services through:

- **First Steps (42%)**
- **Head Start (26%)**

Respondents thought families of children with disabilities were *least likely* to utilize Early Intervention services through:

- **regular preschool (30%)**
- **special education (25%)**

Adequacy of Early Intervention

(60%) regular preschool rated inadequate/fair
(55%) special needs preschool rated inadequate/fair
(61%) First Steps rated good/excellent
(59%) Head Start rated good/excellent

Availability of Early Intervention

More than half of respondents viewed inclusive early intervention opportunities as *not available* or only *somewhat available*.

"Early therapies make a huge difference in how far a child can go in developing to their full potential."

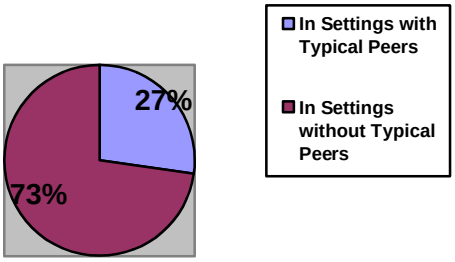
38% of these children to be eligible for special education programs at school age, Missouri is one of only three states which require a minimum of a 50 percent delay in one developmental area to be eligible for early intervention services. Other states, like Kansas, qualify children with a 25% delay in one or more areas. In Missouri, fewer children qualify for early intervention, and more of these children (56%) still require special education at school age.[13]

The First Steps program appears to be caught in a battleground of competing philosophies of effective early intervention. The program underwent a redesign in 2004; however, the redesign had problems with provider misunderstanding and failure to embrace the new philosophy. The new philosophy is one of building family capacity to understand and address issues within daily routines, as opposed to a treatment-based model.

> ***"If they take First Steps away we will have a lot of kids with problems not getting help."***
>
> ***"Parents as Teachers program…can usually detect if the child is not at the level they should be and can refer you to places to receive help."***[20]

Early Childhood Special Education: While enrollment in Missouri public preschools has more than doubled in the last five years,[14] the percent of ECSE students who receive their special education services in settings with typically developing peers has only averaged 27% since 2003.[15]

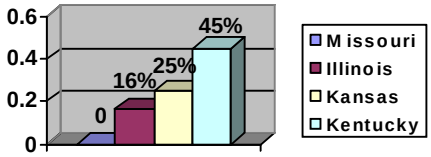
Place of Special Education Service Delivery[16]



Missouri schools will soon be required to report the extent to which students in ECSE are participating in regular education, including participation in educational services not paid for by districts. Currently, schools only report on where children receive special education services.[17]

Funding. In Missouri there is still a great need for a continuous and reliable source of public funding for early learning.[18] Missouri's lack of financial commitment to early childhood programming can be seen in the fact that Missouri was one of only a handful of states with pre-K programs who did not increase pre-K funding for FY 2007, as illustrated in the following chart. This lack of state financial commitment only hurts children with special needs.

Percent Increase in Pre-K Funding FY2007[19]



What We Recommend

These recommendations are offered to supplement that which has already been implemented with the redesign of First Steps.

- A dramatic shift is needed towards providing options for early childhood special education within inclusive environments, just as the First Steps philosophy has shifted towards addressing the child within their natural environment. Segregated classrooms are not natural, except in being "naturally" unequal. When self-contained classrooms are required to meet student needs, primary focus should be placed on transitioning towards more natural, inclusive environments as quickly as possible.
- Continue to develop efforts to achieve a uniform philosophy across First Steps providers. Training efforts should be focused on increasing provider skill set in consultative, strengths-based, family-focused therapy. Presence of this skill set should not be assumed as most providers were trained in traditional therapy approaches.
- Ensure that all young children from birth to age five have access to high-quality care and learning opportunities at home and in other settings. Offer incentives for child care providers to increase high-quality, inclusive child care services for children from birth to age three, as this is a natural environment for many children.
- As recommended by the Missouri auditor, a cost-benefit analysis should be conducted, which would allow DESE to determine the feasibility of broadening eligibility criteria for the First Steps program, possibly reducing usage and costs of the ECSE program.
- Outcomes for First Steps families, and quality assurance indicators, should be carefully measured following the implementation of the redesign philosophy, to ensure that the quality of services remains consistent and to identify areas of need for further redesign and provider training.

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EDUCATION

"We, the people of Missouri, believe that diversity enhances our culture; therefore, we commit our resources and efforts to accept, educate, and support all children and youth. All children and youth, being of diverse backgrounds and abilities, will have access to all learning activities with accommodations and supports to succeed. "[1]

Our Beliefs

The Missouri Planning Council for Developmental Disabilities (MPC) mission is to assist the community to include all people with developmental disabilities (DD) in every aspect of life. The Council considers education to be a priority based on the data from the Statewide Needs Assessment and the level of impact that education has on the lives of individuals with DD. A quality, inclusive educational experience will impact individuals' ability to live in the community, obtain integrated employment with comparable wages, and be fully included in the community.[2]

MPC Beliefs

- ***People who have DD should receive individual and family supports which are flexible, based on need, and provided in a culturally sensitive manner.***
- ***Students with DD should be able to attend school with their peers in regular classrooms and neighborhood schools.***
- ***Students with DD should receive individualized supports in a truly inclusive setting that will enable them to develop the necessary skills to reach their full potential to become independent upon leaving the school system.***

What the Research Says

The Individuals with Disabilities Education Improvement Act (IDEA 2004) mandates the opportunity for students with disabilities to receive a free, appropriate public education. The law, which guides how states and school districts provide special education services, has been revised many times since its enactment in 1975, with the most recent amendments made in 2004. As of 2004, over six million students in the U.S., ages 6 through 21, were receiving special education and related services.[3] The No Child Left Behind Act (NCLB), now also requires states to report the scores of students with disabilities on state reading and math assessments, and includes special education students in expectations for proficiency in reading and math and "adequate yearly progress".[4]

Funding issues persist. When IDEA was passed in 1975, the law included a commitment to pay 40% of the average per-student cost for every special education student. That commitment has never been met. Congress is currently funding IDEA 2004 at less than 18%. NCLB is similarly under-funded.[5] Meanwhile, the U.S. Department of Education has no data or other information needed to address questions about the costs and fiscal planning needed to better inform how states and localities allocate funds to provide special education services.[6] Research is needed to address student outcomes in relation to the resources invested.

Over the last 30 years, special education, within the context of federal and state special education law and NCLB, has moved from primarily separate schools and programs to inclusion into neighborhood schools and general education programs, with dramatic change in access to the general education curriculum and higher expectations for academic achievement. Persistent gaps in academic performance still remain, however, between students with and without disabilities, particularly for secondary age students, despite improved outcomes overall.[7]

While increased accountability is addressing achievement gaps, many teachers still believe that access to general education is not appropriate for students with significant disabilities, and that students should "earn" their way into general education.[8]

The State of the State in Education

Inclusion. In 2005-2006, over 900,000 students attended Missouri public schools (K-12), and

What Missourians with DD and Their Families Are Saying[9]

Statewide Needs Assessment Results

Respondents felt that most students with DD (46%) spend their time in a special public school setting rather than an inclusive classroom.

Challenges in Education (Note: IEP= Individualized Education Program)

- **IEPs that seemed to be developed prior to the IEP meeting**
- **Teachers who had not read the student's IEP and were unaware of supports they should be providing**
- **No follow-through in providing the supports indicated in the IEP**
- **Lack of resources that limit the opportunities for students to benefit from needed supports and services**

Adequacy of Education

- **Private or home school education rated inadequate/fair**
- **Special public education rated good/excellent**
- **Inclusive education rated inadequate/fair**

Availability of Educational Opportunities

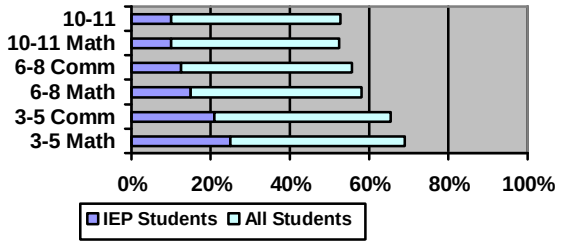
- **66% of respondents felt that inclusive education opportunities were either *not available* or only *somewhat available***
- **71% of respondents felt that transition services were either *not available* or only *somewhat available***
- **78% viewed post high-school community educational opportunities as *not available* or only *somewhat available***

14% received special education services at a per pupil expenditure of $8,221.[10] 36 other states spend higher amounts of money than Missouri on elementary, secondary, and higher education as a whole.[11]

> ***"My son has been segregated in a room by himself with teacher aides…they have had no plan to get him back into the classroom."[12]***

Despite advances in inclusion, gaps in achievement for students with IEPs remain. While the nation celebrates "all-time highs" in reading and math achievement and narrowing of the achievement gap for minority students,[13] an average of only 16-19% of students with IEPs demonstrate proficiency on Missouri Assessment Program (MAP) communication arts and mathematics testing as shown below.[14] This falls below the target rates for this year and well below the current target of 75% proficiency for 2010-2011 as shown below.[15]

Achievement Gap as Demonstrated by 2006 MAP Scores by Grade Level



Missouri is currently one of only two states in the country that operates state-sponsored "schools for the severely handicapped".[16] Missouri currently maintains 36 of these schools, established through state law to serve Missouri students with severe disabilities ages 5 to 21 when the local school district is unable to meet the child's educational needs.[17] 3.6% of Missouri students with IEPs, more than 1,000 students, were served in these separate settings at the end of 2006.[18]

Meanwhile, the national State Directors of Special Education stated that "placing students with severe disabilities in a local district setting, with access to regular educational classrooms, while participating in some general education curriculum" was best practice. They stated that "although many of these students were typically in self-contained classrooms, they should have access to the regular educational classroom and not be served via separate facilities."[19] Unfortunately, per federal law, in cases where parents challenge their child's placement in segregated schools and lose the due process proceeding, they may be responsible for the legal costs of the school district.[20]

Overall, 85% of Missouri parents agree to keep their child with severe disabilities in their local school district, often because they feel "their child would benefit from the integration with non-disabled peers and in fact wanted their student to spend as much time in the regular classroom as possible."[21]

Teacher Preparation. Change cannot occur without education of teachers regarding inclusive practices. The training provided to those entering the field needs to be updated so that those entering "regular" education, understand they are able to provide the accommodations a child needs to succeed in the typical classroom setting.[22] MPC has aimed to increase the number of general and special teachers trained in disability issues.[23] Improving teacher quality is also important if vocational education is expected to alter its mission to truly prepare students for work or continued education.[25]

> ***"Teachers and administrators lack the education about specific disabilities and are not receptive to training or packet information."[24]***

Post-secondary Transition. In order to prepare students for graduation and transition to adulthood, students age 16 and older are expected to have coordinated, measurable, annual IEP goals and transition services that will reasonably enable them to meet their post-secondary goals. This is occurring for less than half (45%) of Missouri students.[26]

According to DESE, 79% of graduates with IEPs were employed or enrolled in continuing education six months after graduation in 2005.[27] However, no information was provided as to type of employment or wages earned. It should be noted that a significant number of persons with disabilities are "employed" in sheltered workshops run by DESE earning an average wage of $2.31/hour.[28] Long-term follow-up information is needed to determine whether these graduates have the skills needed to persist in schooling and employment. The degree to which personal-planning is being conducted is also unknown.

> ***"Should prepare and transition a person with a disability to life and work after high school (as part of their educational support)."[29]***

At the high school level, emphasis tends to be placed on academic improvement versus vocational education.[30] "There is a real need for more community-based programming for individuals as they transition from the children's system to the adult system,"[31] such as opportunities for career exploration including volunteer and paid work experiences. After high school, only 6% of Missouri youth with disabilities attended vocational, technical, or business schooling in 2003.[32]

A remaining challenge is the need to educate and prepare businesses and train them in respect to the

reliability, ability and productivity of employees with disabilities.[33]

What We Recommend

Inclusion

- The nation recognizes that inclusion is no longer simply the responsibility of special educators, and mere physical inclusion in classrooms is not an acceptable outcome. An interdisciplinary workgroup of stakeholders should be convened by the State Board of Education to determine effective inclusion practices for Missouri, barriers to inclusion, and targeted training needs for both general and special educators.
- DESE should focus on defining social skills curriculum, due to its primary importance to employability.
- Staff commitment to inclusion philosophy is key. DESE should design school-based training opportunities through the regional professional development centers in which administrators, teachers, and support staff can be involved in planning for increased inclusion and consider use of multiple teaching/learning approaches like co-teaching by general and special educators.

Teacher Preparation

- The ability to provide effective, inclusive, educational opportunities for Missouri students is dependent upon increasing the capacity of staff via pre-service and in-service training. Effective practice strategies for working with students with special needs within the general education setting should be a focus within pre-service and professional development education.
- In order to ensure that general education teachers entering the field are prepared to meet the diverse learning needs of all students, pre-service training should address:
    - The range of types and degrees of accommodations teachers may be implementing to support the various ways in which students may access the general curriculum.
    - Training in teaming; working with para-professionals.
    - Understanding various "hidden disabilities".
    - Reconciling attitudes around the inclusion of students with disabilities in general education.
- Provision of opportunities during pre-service learning to work with students who have diverse learning needs, with opportunities for reflection on strategies for including all students.
- School districts should receive recognition for attaining and maintaining exemplary levels of inclusion.

Post-secondary Transition

Missouri echoes the nation in its need for coordinated, educational systems change in the development of college preparatory and vocational programs for middle and high school students.

- Educational staff should be made aware of the range of opportunities for community-based, paid employment in order to achieve a broader perspective of what can be created even for students with complex needs.
- There is a need for engagement in person-centered life planning processes for Missouri students. Additional opportunities should be created for parents and students to learn about transition planning, similar to the new transition class offered by MPACT.
- Expand cooperative work experiences for the school districts that don't provide those programs. Expand integrated, competitive and supportive community-based work experiences within the districts that do provide programs.
- Given that the Missouri State Performance Plan for special education targets an increase in the percent of youth who have IEPs and have been *competitively employed* post-school, then planning for post-secondary transition should include:
    - Teaching of self-determination skills in order to appropriately plan for the future and to make educated, informed choices.
    - A strong focus on completing high-school and encouragement to pursue higher-education, given the strong correlation between level of education and employment outcomes.
    - Work that is paired with the educational skills needed for employment, such as basic literacy and social skills.
    - A presumption of *ability to work* held by all those involved in a student's education and post-secondary transition planning.[34]
- DESE's web site for the State School program should include information about community living and employment resources, in addition to the resources posted for evaluating long-term care facilities and day habilitation programs. MPC should work with DESE to ensure that the state is communicating well-rounded resource information on the DESE web site, as well as the website of other agencies utilizing public funds.

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EMPLOYMENT

"The dignity, responsibility, and economic independence resulting from gainful employment is the most effective way of reducing dependency on public benefits, enhancing self-reliance, changing attitudes, and promoting community acceptance of persons with disabilities."[1]

Our Beliefs

The Missouri Planning Council for Developmental Disabilities (MPC) believes individuals with developmental disabilities (DD) have the opportunity to be successful in obtaining and maintaining integrated competitive employment.[2] These individuals work in the competitive labor market on a full or part-time basis in an integrated setting and receive fair compensation. MPC feels that employment must be a priority for its five-year plan, based on its recent Needs Assessment and other research.

MPC Values

- **People with DD have contributions to make in our communities that are equal in worth and value to those of other citizens.**
- **People with DD have the opportunity—as do other citizens—to find and hold competitive jobs and/or otherwise contribute to the community.**

The results of MPC's Needs Assessment indicate the majority of respondents believe individuals with DD spend their time in sheltered employment or in non-employment situations. Participants describe major problems with the availability of job opportunities, employer attitudes and lack of understanding, and transportation to work. The lack of accessibility and accommodations needed for work, and insufficient capacity of employment providers in areas like job training, are also barriers for some individuals.[3]

***Note: The Needs Assessment states where respondents believe individuals with DD spend their time; it may not mean they choose to be there.**

What the Research Says

In recent years, powerful legislation such as the Americans with Disabilities Act (ADA) has drawn focus towards the need to increase opportunities for supported employment of persons with disabilities within competitive work settings in which most persons do not have disabilities. U.S. labor economists predict a declining workforce and a continued increase in employment rates from now to 2014.[5] These trends create a favorable climate for persons with disabilities looking to enter or re-enter the workforce.

However, the Administration on Developmental Disabilities (ADD) reports concerns regarding how little information exists from agencies in reference to how persons with disabilities perform in their employment settings and how long they stay employed.[6] One factor regarding the difficulty in obtaining data is that most federal and state Vocational Rehabilitation (VR) agencies do not follow people long term if their employment placement is successful.[7]

What is known about the minority of persons with DD who have been able to attain integrated employment is that most are young (age 22-30), work in individual jobs as opposed to group jobs (81%), work part-time, earn incomes above minimum wage, have paid time-off, and occasionally have access to health plans. Persons in individual jobs show the strongest outcomes with higher wages, and a higher likelihood to have paid time-off and healthcare benefits.[8]

ADD also states the great need for systemic change in order for individuals with DD to acquire paid, integrated employment.[9] Braddock (2005) cites at least eight studies that show how movement from

What Missourians with DD and Their Families Are Saying[4]

Statewide Needs Assessment Results:

- **79% of respondents thought persons with Developmental Disabilities (DD) they knew were either *not employed* or were *employed in sheltered workshops* (Note: average hourly sheltered workshop wage is $2.35/hour in Missouri)**
- **Only 21% of respondents indicated that people were likely to participate in support employment (8%) or competitive employment (13%)**
- **Over half of the respondents felt options for employment in the community without supports were inadequate**
- **40% of the respondents felt that supportive employment options were inadequate**

Challenges in finding employment:

- **Perception that appropriate jobs were not available (53% of respondents)**
- **Family responsibilities**
- **Inadequate training**
- **Fear of loss of benefits**
- **Fear of lack of access to opportunities for on-the-job training or job promotion**
- **Discouragement by family and friends**

sheltered to supportive employment benefits persons with DD as well as taxpayers.[10] Innovative programs like that found in Montana have helped fund micro-enterprises to create self-employment for students with disabilities.[11]

The State of the State in Employment

It is our finding that the Department of Elementary and Secondary Education (DESE), Vocational Rehabilitation, and state agencies in Missouri all track data on employment separately. Therefore, there is no comprehensive data on employment that takes into consideration all students and adults in the state who are currently employed or not.

Improving opportunities for work is a key factor in impacting community inclusion for persons with DD, as lack of work can ultimately lead to isolation and segregation from the community.[12] Yet, despite a legal mandate for equal employment opportunities, a declining workforce, and notable progress in other states, there still is a lack of employers willing to hire persons with disabilities in the Missouri labor market.

Low Employment Rate. In stark contrast to the concerns regarding an impending lack of workers, Missouri's employment rate for persons with disabilities is only 39%, as opposed to an 81% employment rate among Missourians without disabilities, yielding a gap of 42%.[13] Several studies across the nation have shown that up to ¾ of people with DD who are without employment would actually like to work.[14]

Inadequate Employment Options. In 2001, sheltered workshop placement was ruled to be an unacceptable "employment outcome" for Vocational Rehabilitation per federal regulations.[15] Missouri's VR program has not completed any placements in sheltered workshops since 2002. Yet, in 2005, 7500-8000 persons with disabilities were working in the 93 sheltered workshops in Missouri through the (DESE) Sheltered Workshop program.[16]

In FY2006, Missouri workshops reported expenses of over $121 million dollars including materials, labor, administration, and operating costs. State and county aid covered $29 million of these expenses. Despite strong government investment, monetary value to workers has remained stagnant. Employee wages only increased by $.02 from 2004-2006.[17]

Limited Growth in Missouri Sheltered Workshop Wages Over Past 24 Years

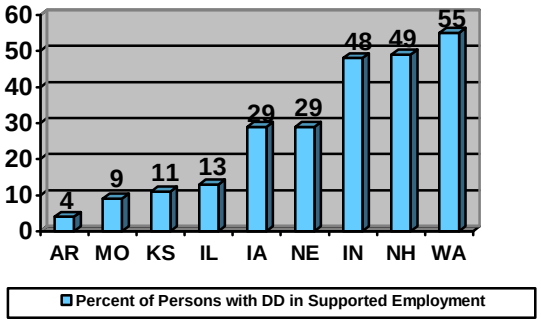
(adjusted for inflation)[18]

Year	1982	1986	1993	2005
Average Hourly Wage	$.88	$.96	$1.47	$2.31

While sheltered workshops provide a place of employment for many Missourians with disabilities, their wages – adjusted for productivity of workers- continue to fall far below the minimum wage. The benefits gained from the expense to operate the workshops must be questioned in light of these meager wages, particularly when these funds could be used to create and support integrated, community employment.

Integrated and Supported Employment. In 2004 Missouri was still directing 93% of MRDD "total funding for day employment" to facility services and non-work placements and only 6% to integrated employment.[19] 2005 data also shows only 9% of Missourians with DD in day-work programs participate in supportive employment (SE) settings, a percentage that **places Missouri in the three lowest states**. Among the states below, spending per capita for SE ranges from $.09 in Arkansas to $3.56 in Washington, with Missouri spending a mere $.29 per capita.[20] Furthermore, only 17% of total successful VR case closures in 2004 consisted of SE placements, a figure essentially unchanged over the past 10 years, as 15% of successful closures were SE placements in both 1995 and 2000.[21]

FY2004 Supported Employment



NOTE: The chart above compares FY 2004 supported employment figures for Missouri, the states surrounding Missouri, and two states with exemplary supported employment (Washington, New Hampshire). (Braddock, 2005, pg. 42)

State Policies Create Dependency and Disincentives to Work. Federal policy allows individuals to have up to $2,000 in assets (e.g., money in a savings account, SSI, earned income, etc.). However, in Missouri, persons with disabilities lose supports if they have over $999.99/month in assets including government benefit income; thus, dramatically limiting what they can earn per month. People who earn money that would take them over the $999 amount are usually urged to spend their "excess" income to avoid losing Medicaid benefits.[22] This is called "spending down." The number of persons in the spend-down program doubled between 2005-2006.[23] Policies like these require persons to be poor and stay poor in order to qualify for Medicaid, instead of allowing persons to earn a living wage, to save, and to plan for reduced dependence on government assistance.

The state legislature eliminated Missouri's Ticket to Work program, Medical Assistance for Workers with Disabilities (MAWD), in 2005 and put no tracking mechanism in place to determine the effects on persons with disabilities. 18,000 persons were cut from the program, and 9,529 persons completely lost medical coverage. 8% of these reported that they would have to stop working in order to qualify for Medicaid benefits.[24] Therefore, our current state policies seemingly create a cycle of dependency for persons with DD.

"Although local employers are sympathetic, they appear unwilling to offer jobs to people with DD, even when the person has marketable skills."[25]

What We Recommend

Everyone deserves to have a choice about how they can best contribute to society. With the appropriate options in place, people can not only improve their quality of life, but can become productive tax-paying citizens who are less reliant on government systems.

- Increase access to the supports needed for individuals with DD to obtain and maintain a job in the communities where they live. Support could include transportation, personal assistance services, or help with finding and maintaining a job.

- Require state agencies to integrate the State Employment and Diversity Curriculum developed through a Planning Council Grant to the University of Missouri Kansas City, Institute of Human Development or a similar training program into new employee training so as to educate all state employees on supporting people with disabilities to work.

- Partner with the Missouri School Board Association and teacher education programs to identify and increase the level of Disability Awareness training for all local school employees.

- Develop a cooperative relationship with DESE to develop strategies, incentives and increased flexibility of funding to encourage individuals and organizations to transition towards competitive employment in integrated settings.

- Remove disincentives to employment by allowing people with disabilities who make up to 150% of the Federal Poverty Level to keep their medical benefits. Allow individual who earn above this level to buy into a medical plan that is consistent with Federal guidelines and emphasized competitive employment in integrated settings. Develop a sliding scale for individuals with disabilities who earn over 150% of federal poverty level.

- Increase access to information and training on evidenced-based practices on community-based employment to individuals with DD, parents, employment service providers, and policy makers.

- Encourage state and private agencies that provide individualized case management for individuals with disabilities to receive training on the Workplace Personal Assistant services and educate individuals and families on the availability of these services.

- Provide training to develop a qualified labor force to support individuals with disabilities in finding and retaining employment through state agency efforts and through the MPC supported program, the College of Direct Support.

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HEALTH CARE

"The reality is that for too long we provided lesser care to people with disabilities. Today, we must redouble our efforts so that people with disabilities achieve full access to disease prevention and health promotion services."[1]

Our Beliefs

The Missouri Planning Council for Developmental Disabilities (MPC) maintains a primary goal for 2007-2011: People are healthy and benefit from the full range of needed health care services. The MPC has supported, and continues to support training to increase knowledge about DD among health care professionals.[2]

MPC Beliefs

- ***People with DD, family members and others are confident that publicly-funded services assure and promote good health and individual well-being.***
- ***The system is responsive to individual needs, providing help when and in the manner that people need assistance.***

What the Research Says

Health care "means that persons with disabilities can access appropriate, integrated, culturally sensitive and respectful health care that meets the needs of a whole person, not just a disability."[3] People with disabilities in general often have poorer health care outcomes. People with DD report higher levels of unmet health care and mental health care needs than people without functional limitations.[4]

Uninsured. The number of uninsured persons has risen to 46 million Americans,[5] greater than the combined population of Missouri plus the eight states that surround it. Approximately 11-12% of persons with intellectual or developmental disabilities do not have insurance according to a national health survey.[6] People without health insurance receive about half as much medical care as the insured.[7] Therefore, they use less preventive care, are diagnosed at more advanced disease stages, tend to receive less care once diagnosed, and have higher mortality rates than insured individuals.[8]

Access. The health care rights of people with DD, and protection from discrimination in health care, are ensured in the Americans with Disabilities Act of 1990 (ADA) and Section 504 of the Rehabilitation Act of 1973.[10] However, it is often difficult for persons with DD to find specialized medical care. To facilitate access to specialists, people need to have the continuity of a primary care physician, choice of doctors, and access to out-of-plan care. People with disabilities and their families often feel that doctors and hospital staff are uneducated about disabilities and therefore may not be reliable or respectful. People with disabilities may also have difficulty finding physically accessible health care facilities.[11] Finding dentists for persons with DD is recognized as a serious problem nationwide, particularly for persons who have an intellectual component to their disability, in part due to difficulty finding dental providers who accept public dental coverage.[12] In 2002, 36% of children and adults with disabilities had annual dental visits, compared to 46% of persons without disabilities.[13]

The Surgeon General outlined the following Call to Action Goals in 2005:[14]
1) People nationwide understand that persons with disabilities can lead long, healthy, productive lives.
2) Health care providers have the knowledge and tools to screen, diagnose, and treat the whole person with a disability with dignity.
3) Persons with disabilities can promote their own good health by developing and maintaining healthy lifestyles.
4) Accessible health care and support services promote independence for persons with disabilities.

Costs. Medicaid is a primary source of health care for many persons with disabilities, often providing

What Missourians with DD and Their Families Are Saying[9]

Statewide Needs Assessment Results
Respondents thought people with DD were *most likely* to get health care services through:
- **Doctor's office (62%)**
- **Hospitals/emergency rooms (22%)**

Respondents thought people with DD were *least likely* to get health care through:
- **Residential health care center (42%)**
- **Local health departments (21%)**
- **Community health clinics (16%)**

Health Care Help/Support
Respondents most frequently reported receiving supports from doctors and other medical professionals, and some reported no problem finding medical and/or dental care.

Adequacy of Health Care
Respondents rated the health care options that they were *most likely* to use as *inadequate/fair,* and the ones they were *least likely* to use as *good/excellent.*
(70%) Hospital/emergency room rated *inadequate/fair*
(67%) Doctor's office rated *inadequate/fair*
(51%) Residential health care center rated *good/excellent*
(43%) Community health clinics rated *good/excellent*
(41%) Local health department rated *good/excellent*

Availability of Health Care
(75%) of respondents viewed health care as *only somewhat/not available*
(73%) rated dental services as *only somewhat/not available*

Top Challenges in Health Care
- **Public health insurance program issues**
- **Lack of nearby dental service**
- **Lack of nearby medical resources**

insurance for those who otherwise would be uninsured. A national health care survey revealed that 43-60% of persons with intellectual and/or developmental disabilities utilize public health care plans.[15] As Medicaid costs continue to increase, states have implemented cost containment measures typically focused on reducing eligibility, resulting in loss of health coverage for many Americans.[16] Yet, Medicaid spending per person grew more slowly than spending under Medicare and private insurance between 2000-2003.[17] Medicaid also has a significant positive effect on state economies because it brings in matching federal funds.[18]

Since 2000, health insurance premiums have grown 78%, while wages have only grown by 20%. Health insurance for individuals now averages $4,242 yearly, and $11,480 for family coverage.[19] Only a little over half of employers now offer health insurance,[20] as jobs have shifted towards the service sector and part-time jobs, which both offer less benefits. Yet, data shows that 2/3 of children with special health care needs rely on insurance through the parent's employer, which often doesn't cover the mental health care and physical therapy sometimes needed by children with DD.[21]

"[My] employer discontinued [insurance plan] because of increase in premiums when employee had child with Down Syndrome."[22]

Health care through private insurance has become more inaccessible for individuals with DD due to higher premiums, deductibles, and co-pays. In the absence of a national health care policy, states will be forced to choose between continuing coverage using limited funds, further impacting state revenue; or continuing to reduce coverage for low-income families, further impacting the numbers of uninsured and generating poorer health outcomes.[23]

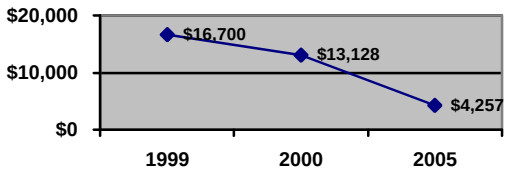
The State of the State in Health Care

Medicaid in Missouri plays a primary role in providing insurance for the poor, and long-term care for the elderly and persons with disabilities.[24] In 2005, the legislature in Missouri enacted changes to the number of persons eligible for the Missouri Medicaid program, and specified sunset dates for the Missouri Medicaid and the State Children's Health Insurance Programs (SCHIP) of June 2008. Coverage of many of the optional Medicaid services for states were also eliminated by the Missouri legislature[25] --services such as dental care, dentures, podiatry, orthopedic devices, hearing aids, eyeglasses and comprehensive day rehabilitation services,[26] which are vital to the independence and productivity of Missourians with disabilities.[27] Approximately 115,000 Missourians lost coverage, or one in every eight persons insured by Medicaid.[28]

In addition, the income limit to qualify for Medicaid was reduced from 100% of the federal poverty level to 85% resulting in larger "spend downs" to be eligible for Medicaid. The number of persons in the "spend down" program doubled between 2005-2006.[29] This keeps people from moving toward economical self-sufficiency. Many others who are still eligible for Medicaid must pay large monthly "spend downs" in order to remain eligible. Federal policy allows individuals to have up to $2,000 in assets (e.g., money in a savings account, SSI, earned income, etc.). However, in Missouri the limit is only $999. Therefore, people who earn money that would take them over the $999 amount are required to spend their "excess" income to avoid losing Medicaid benefits.[30]

Missouri has also made considerable, detrimental eligibility changes since 2000 to Medicaid for working parents, as shown below.[31] Of all states making Medicaid changes for cost containment reasons, Missouri removed the most working parents from the program at 68,000.[32] These changes affect children with developmental delays that might not be caught early due to lack of doctor's visits.

Decreasing Eligibility of Low-Income, Working Parents for Medicaid[33]



Allowable Annual Income for 4-Person Family

In 2008, Missouri will need to either move to extend the sunset dates, or reform the current system, opening the door to consideration of sweeping reform such as the universal health insurance coverage recently enacted in Massachusetts.[34]

Among the Medicaid changes was elimination of the Missouri Aid to Workers with Disabilities (MAWD) program, which enabled people with disabilities to work, yet still be able to purchase affordable health care and personal assistance services on a sliding fee scale. The total number of individuals who lost coverage under MAWD is 18,000. 9,529 persons with DD were left completely uninsured. Despite their lack of insurance, most respondents indicated that they wanted to remain working, but 8% indicated they would need to quit in order to re-qualify for Medicaid. No measures were instituted to track the effects of these decisions on those that lost insurance coverage.[35]

The number of adults and children with DD in Missouri who go without dental services is unknown. For every dentist that accepts Medicaid/SCHIP, there are more than 1,000 children enrolled in the program in the St. Louis area alone. Reimbursement rates are so low that there is no incentive for dentists and doctors to accept these patients.[36]

There is an economic impact from lack of insurance in lost earnings due to fewer years of healthy life and lower productivity while at work. "These economic costs are substantial and represent a hidden cost of uninsurance, over and above the cost of the medical care used by the uninsured."[37]

What We Recommend

Accessible, Affordable, Quality Health Care

- Expand home and community-based services and cover and equipment and services needed for independence. Currently, individuals in need of some services or medical equipment can only receive them in an institutional setting. The need for a single piece of equipment or service could force an individual into a facility, when they could otherwise remain in their home if that same service or equipment were covered in the community.
- Cover dental, personal care, podiatry, rehabilitation, specialty care including durable medical equipment and other services identified as optional by the Centers for Medicaid and Medicare. Denying these essential services moves people toward costly and unnecessary institutional care.
- Offer qualified workers with disabilities the opportunity to buy into a state sponsored health insurance plan. The buy-in rate should be reasonable for the cost of the plan to provide a clear incentive to work. This moves people towards independence, productivity and fulfillment and carves a path out of poverty.
- Reform the spend-down policy to avoid forcing people into poverty, and change to a premium-based approach to encourage productivity and growth. An individual or family should not have to choose between health care and other basic necessities. Expenditures for health insurance should be affordable and premium based depending on income.
- Change asset limits to at least $2,500 for an individual and $5,000 for a couple. This would allow individuals with disabilities to be able to cope with an unexpected emergency, bill, necessary purchase or to save for a home or car down payment.
- Increase the amount of state-funding that is matched with federal Medicaid funds. Missouri has the 10th highest percentage of unmatched MR/DD state funds.[38]
- Increase funding for medical services for people with DD who do not have access to affordable health insurance and do not qualify for Medicaid.
- Improve physical accessibility of health services and medical equipment so that individuals with DD obtain quality assessment and treatment. People currently have to be assessed and treated in wheelchairs.
- Work with other states in developing standards for medical equipment accessibility under ADA.

Professional Education

- Increase training for health care professionals so they are knowledgeable about working with persons with disabilities, reduce stereotypes, and improve communication between health professionals and persons with DD.[39]
- Partner with state departments, legislators and advocates should partner to do the following:

  1) Identify health care gaps and barriers. Develop and implement specific strategies to address the needs of people with DD.

  2) Recruit professionals to underserved areas to increase access.
- Partner with health care professionals and medical schools and utilize the Missouri Developmental Disability Resource Center to develop resource fact sheets for health professionals, with tips for working with persons with disabilities in health care settings.
- Recruit doctors with experience in working with people with disabilities to train other doctors about health care for persons with DD. They should be educated on ways to deliver quality healthcare to persons with DD in partnership with the individual and people who know them best.

Health Care Advocacy

- Include persons with disabilities in public health advisory groups, as is currently being implemented in Montana.[40]

HEALTH CARE ENDNOTES

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HOUSING

"…Americans with disabilities are entitled to the same range of choices and opportunities as other citizens. This includes being able to decide where and with whom to live, and how to spend time. These simple choices, generally taken for granted, are not afforded to people with disabilities…"[1]

Our Beliefs

One of the primary goals of the Missouri Planning Council for Developmental Disabilities (MPC) is to have "Individuals reside where and with whom they choose in non-segregated community settings with the availability of individualized supports."[2] This goal was created from values that are gaining acceptance across the state and nation.

MPC's Needs Assessment indicates individuals with developmental disabilities (DD) and their families feel that there are significant problems and challenges with insufficient accessible, affordable, and safe community housing; insufficient in-home supports and services; long HUD (Housing and Urban Development) housing waiting lists.[3]

MPC Values

- **To assist the community to include all people with developmental disabilities (DD) in every aspect of life**
- **Improve the lives of persons with DD through programs and services which enable those persons to live independently and productively, given their individual needs and capabilities**
- **Supports community initiatives that result in persons with developmental disabilities having opportunities for housing.**

What the Research Says

Research supports the nationwide trend to increase community-based living opposed to institutional care. The Olmstead ruling by the Supreme Court in 1999 states that it is a violation of the Americans with Disabilities Act (ADA) for states to discriminate against people with disabilities by providing services in institutions when individuals could be served more appropriately in a community-based setting.[6]

Supported living is "the fastest growing residential option for persons with DD in the U.S.," increasing 19% from 2002-2004.[7] Multiple studies conducted over the last 20 or more years, of people moving from institutions and into the community have found decidedly positive results. According to some studies, residents of institutions in other states sometimes said they did not want to leave the institution. **However after moving they reported strong satisfaction and happiness within their community home.**[8]

The State of the State in Housing

In Missouri, a shared vision appears to be emerging across state agencies regarding the need for creative reform of Missouri's long-term care system. In 2006, Missouri received a $3 million dollar, 5-year federal grant targeting transformation of long-term support services in Missouri that aims to recreate the system to improve outcomes for both consumers and providers.[9] Missouri Protection & Advocacy Agency (MO P&A) also supports community-based living and recommends "families should be involved at every step and decision point."[10] *Show-Me Change*, a report produced in 1998 by MPCDD, determines all services and supports should be designed around

What Missourians with DD and Their Families Are Saying[4]

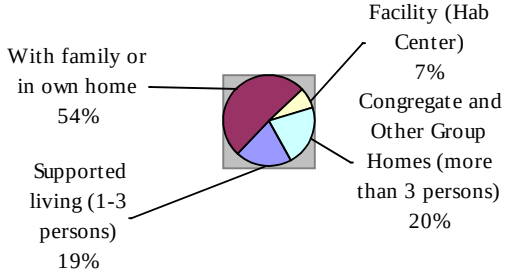
Needs Assessment Results

- **57% of respondents thought persons with Developmental Disabilities (DD) were *most likely* to live at home with family and friends**
- **48% thought people with DD were *least likely* to live in a place of their own**
- **70% of respondents rated community-based living opportunities as "inadequate" or "fair"**

Challenges in finding a place to live included:

- **Need for more in-home supports and services. Long waiting lists for HUD housing and other community programs**
- **Challenges of living on one's own in the community**
- **Impact of community and housing industry perceptions**

Place of Residence- Missouri, 2006[5]



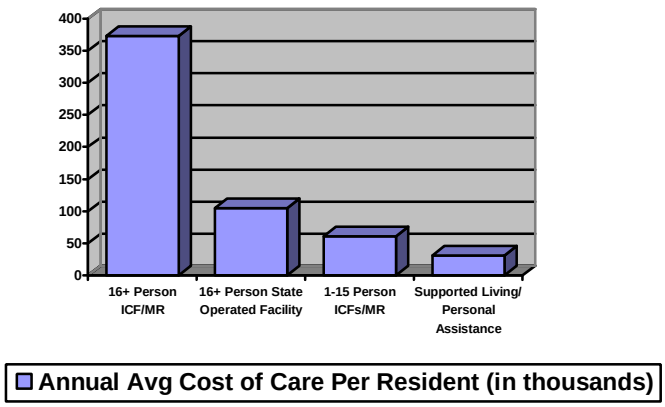
achieving a maximum level of community inclusion, and the planning process should be truly "person-centered."[11] Governor Blunt restated in 2006 that he supports "private-sector community placement through closure of the state-operated Bellefontaine Habilitation Center."[12]

Despite the presence of numerous federal, state, and local programs and federal legal provisions addressing housing, significant barriers still exist including: **1**) the lack of available, accessible housing, **2**) the number of persons waiting for these programs, and **3**) consumer understanding of the programs and of their legal rights. Here are the facts from 2004:

"Because most people with disabilities have fixed incomes, we can't afford apartments and we're stuck. Even though I am working, I can't afford my apartment and I can't afford to move either."[13]

- Missouri is one of only eight states that reported a decrease in spending for supported living and personal assistance.[14]
- Missouri ranks within the 10 lowest states for use of 1-6 person residential settings.[15]
- Cost of care to adults with DD in Missouri steadily decreased across all settings; supported living with personal assistance being on average the least costly to implement.[16]

Cost of Residential Options in Missouri FY2004[17]



- Missouri still ranks 38th in average daily number of residents in institutions.[18]
- Use of nursing facilities for Missourians with DD was 58% greater than the nationwide rate.[19]

Dilemma of Aging Caregivers. It is estimated that in the United States 75% of people with developmental disabilities live at home with their families, with the primarily caregiver being over the age of 60 in 25% of these homes.[20] In Missouri, 15,201 persons with developmental disabilities were estimated to be living with caregivers over the age of 60.[21] This number signals an emerging crisis within the state as aging caregivers become unable to care for their loved ones with developmental disabilities and out-of-home placement becomes necessary, given the already crowded waiting lists.

"Biggest area of concern is 'What happens when we are gone?", and "My son lives with me but I am concerned about his care when I am gone."[22]

What We Recommend

These recommendations are meant to enhance the objectives already stated within the Transformation Grant and other current housing initiatives.

- Priority should be placed on expanding the availability of accessible, affordable and safe housing options within the community.
- Locate affordable and accessible housing options in places that optimizes access to community resources and services.
- Separate funding for housing from funding for supports to maximize individual control
- Explore blended funding to increase housing and support options for people.
- Develop a plan to meet the housing and support needs for individuals with caregivers over 60 years of age to prepare for the fiscal demands required to meet the impending need.
- Increase access to HUD Section 8 vouchers.
- Work with other partners such as Centers for Independent Living and Comprehensive Psychiatric Services to coordinate state, federal, and local housing initiatives.

HOUSING ENDNOTES

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RECREATION AND SOCIAL OPPORTUNTIES

"When people with disabilities are not included in…activities, the activities do not represent the whole community. Everyone suffers when certain parts of a community are excluded because each of us has something of value to share. Real inclusion comes only when programs and individuals welcome and include all persons who wish to participate, recognizing their talents and not their disabilities."[1]

Our Beliefs

The Missouri Planning Council for Developmental Disabilities (MPC) believes that persons with disabilities should be given opportunities to make informed choices about where they play, and socialize, and worship. Essentially, they should be able to choose to participate in activities that are meaningful to them, when they want to. Additionally, people should receive individual and family supports which are flexible, based on need, and provided in a culturally sensitive manner.[2]

What the Research Says

Recreation is defined as the refreshment of the body and mind. Any activities that provide a break from the more mundane aspects of life, in order to foster physical, mental and spiritual wellness, are recreational.

Opportunities to build social capital. Inclusive recreation, in whatever form it takes – sports, worship, dinner and a movie, classes, fishing, coffee with friends- affords people the opportunity to build "social capital". Social capital is the network of relationships that bind people together in a spirit of trust and cooperation. One avenue for building social capital is through developing social relationships within recreational activities. It is through social recreation that we meet others, explore how we are similar, begin to establish trust, and discover each other's competencies, talents, and gifts. People then use social capital to help them in finding jobs, additional social opportunities, transportation, and other aspects of life where this network of connections is a valuable tool.

Inclusive Recreation. In 2006, numerous organizations could be located for seemingly every sport in relation to every disability, such as the U.S. Blind Horseshoe Pitchers Association, Waterskiing for the Disabled, and the National Softball Association for the Deaf. However, recreational activities that are inclusive and equal in nature, and provided opportunities to develop social capital, appeared to be less prevalent. Researchers have noted that inclusive recreation achieves the following:[4]

- Encourages and enhances opportunities for people of varying abilities to participate in activities together with dignity in natural settings.
- Builds community capacity.
- Increases awareness of the abilities of persons with special needs.
- Enhances social connections, motivation, and self-esteem.
- Provides more cost-effective recreation for persons with disabilities.

However, there are currently limitations in availability of program options, particularly in the realm of after-school activities and summer programs for children, and lack of inclusive programs for adults with developmental disabilities (DD). Further, it should be noted that while some persons may have access to group recreational outings, they may not be activities that they would prefer, and may not allow individual opportunities to meet people and build social capital.

What Missourians with DD and Their Families Are Saying[3]
Statewide Needs Assessment Results

Recreational Choice
Respondents identified people with DD were *most likely* to use:
(50%) special/segregated recreation and social activities/event
(35%) regular community sponsored recreation and social activities
(15%) accessible community sponsored recreation and social activity

Respondents identified people with DD were *least likely* to use:
(47%) regular community sponsored recreation and social activities
(31%) special/segregated recreation and social activities/events
(22%) accessible community sponsored recreation and social activity

"No transportation to get to what little recreation there is."

Adequacy of Recreation Options
(72%) rated regular community sponsored recreation *inadequate/fair*
(70%) rated accessible community sponsored recreation *inadequate/fair*
(41%) rated special/segregated recreation good/excellent

Availability of Recreational Opportunities
(72%) rated accessible recreation opportunities *somewhat/not available*
(75%) rated social opportunities *somewhat/not available*

NOTE: The Needs Assessment indicates how people with DD may spend their time in recreation, but does not necessarily mean that they chose these activities.

Two recent surveys both found "community participation gaps" between people with and without disabilities.[5] The rate of participation of persons with disabilities in worship or other group community activity appeared to be affected by mobility, as people who were more mobile participated more in the community.

"The schools don't bother to include you. The basketball flyers don't even come home."[6]

Importantly, one survey also found that "at every level of mobility limitation, from none through moderate to most severe, **persons who participated more in the community were more likely to be very satisfied with their lives**." Therefore, outreach from places of worship and other local organizations can enhance both the community participation and life satisfaction of persons with disabilities.[7]

While, overall, people with disabilities report that they are less involved in their communities, they seem to be participating in some specific community activities at similar rates to people without disabilities. Little or no differences exist with respect to participating in community events related to hobbies, participating in volunteer work, attending special community events such as fairs and parades, and attending recreational activities such as sporting events and movies. The largest differences exist between these two groups with regard to involvement in religious services, local politics, cultural events, outdoor activities, and community service organizations.

Health Benefits. Research on the health benefits of recreation for people with disabilities is increasing. According to the Surgeon General's Report on Physical Activity and Health, all persons of all ages, *including those with disabilities*, experience an enhanced quality of life through regular moderate physical activity.[8] Further, the national health initiative, Healthy People 2010, also promotes health and an improved quality of life for persons with disabilities, noting that people with disabilities tend to have lower rates of physical activity and higher rates of obesity.[9] Researchers note that inactivity in persons with disabilities can lead to deteriorating health, increased dependence on others, a decrease in social interactions, and other secondary complications.[10]

Barriers to Inclusive Recreation. Although the Americans with Disabilities Act (ADA) safeguards the rights of people with disabilities to participate in inclusive recreation, individuals face limited access to a range of activities, programs, and services. The major barriers that all people face when trying to increase physical activity are similar to the obstacles that people with disabilities face such as lack of access to convenient facilities, and lack of safe environments in which to be active.[11]

The State of the State in Recreation

Inclusive Recreation. Within Missouri there appears to be an increasing number of recreation programs for persons with disabilities, particularly within urban areas; however many of these programs remain non-inclusive in nature. There is also a lack of research regarding the need for and presence of inclusive recreational opportunities for Missourians with disabilities.

Some Missouri urban counties offer supports for inclusion within Parks and Recreation programs. Others offer opportunities to attend classes in an integrated environment. Several counties offer informational resources for residents regarding available recreation and leisure opportunities. Yet, the limited number of programs available can in no way accommodate the number of persons with DD that could benefit from inclusive recreational programming, especially in rural areas.

Barriers to Inclusive Missouri Recreation. Comments from the Statewide Needs Assessment clearly indicate that accessibility is an area of need. However, there are no comprehensive studies of the accessibility of Missouri recreation for persons with disabilities, at least in regard to physical and worship activities, based on a review of existing research.

Community activities are not always available for individuals with disabilities, particularly within smaller rural communities. While some respondents commented that the majority of recreational activities are separate from others in the community, others worried that there weren't enough programs specifically for individuals with disabilities. Transportation for recreation seemed to be available to persons living in group homes; however, it was a problem for other persons. Even for those in group homes, transportation may not be available to activities that are of individual interest, versus group activities. Affordability of recreational activities was frequently mentioned.

Many organizations that support recreation for persons with disabilities appear to rely on volunteers as support personnel. Reliance on volunteers, while reducing program cost, may create difficulty in stability of support provision. State Needs Assessment comments indicated a general lack of available supports, particularly within rural areas.

What We Recommend

- Advocate that individuals be supported to participate in the social and recreational opportunities afforded in the communities where they live and promote choice as the guiding value when assisting them to participate in leisure or recreational activities.

- Encourage individuals with developmental disabilities, families, service providers, policymakers, and recreational providers to recognize the importance of recreation and social opportunities in developing social capital and its effects on an individual's ability to be included in the community.
- Encourage communities to include people with disabilities in inclusive social and recreational activities and acknowledge the community's success where this is being done. Individuals with disabilities and their families should be included in community planning activities and the development of inclusive social and recreational opportunities.
- Encourage flexibility in participation requirements should be adopted by recreation providers as a value which would allow individual to participate in activities in spite of age, skill level, or ability to pay.

RECREATION ENDNOTES

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SAFETY AND QUALITY ASSURANCE

"We are Americans too! We want to be included in all communities in our great nation and to have all the rights and responsibilities of full citizenship. We need to be safe and free at the same time. We know how to do this. Few American communities are listening."[1]

Our Beliefs

The Missouri Planning Council for Developmental Disabilities (MPC) and other Missouri advocates feel the responsibility of protecting individuals with developmental disabilities (DD) is not only a legal responsibility but a moral responsibility.[2]

The Division of Mental Retardation and Developmental Disabilities (MRDD) supports individuals with DD by engaging in person-centered planning which helps to identify and provide optimal programs and services; thus enabling individuals with DD to live a safer life in the least restrictive setting given their individual needs and capacities.

The results of MPC's Needs Assessment indicate that individuals with DD and their families feel there is still much variance in acceptance in the community and inclusion of people with disabilities. Many people expressed concern that the attitudes and lack of understanding of persons with DD lead to individuals being excluded from the community.[3]

MPC Values and Goals

- **Persons with DD belong in their community.**
- **Quality of life is as essential as safety in regard to an individual's right to choose to live in the community.**
- **Freedom from abuse, neglect, exploitation and violation of human rights.**

MPC Beliefs

- **People with DD have the same rights and responsibilities as other citizens, including the opportunity and responsibility to direct their own lives.**
- **People with DD are listened to and treated equally as other citizens without assumptions based on their disabilities.**
- **The system is an active partner with people with DD and families by providing helpful and accurate information about choices.**
- **Resources for supports in the state of Missouri must be allocated and expended from a person-centered perspective rather than a provider-centered perspective. Individuals must be in control of their allocated resources for services and how they are delivered.**

What the Research Says: *The State of the State in Safety and Quality Assurance*

Four of Missouri's cities recently received national recognition for their economic strength and quality of life.[5] The current realities of quality of life for Missourians with DD, however, do not seem to match this positive report.

Funding. Many individuals who provided testimony in 2006 to the Missouri Mental Health Task Force felt that budget cuts have significantly affected decision-making in the Department of Mental Health (DMH). Consensus was that DMH cannot continue to stretch its dollars and still provide safety and quality assurance for the Missourians with disabilities that it serves.[6] While the MRDD Systems Change Transformation Grant will increase access to community services, the ability to create new services and to maintain those that already exist will be difficult given the direct support crisis.

Safety and Quality Assurance Administration. Some Missourians have expressed concern that competition, rather than cooperation, exists between services provided through state operated facilities and community-based programs, pointing to differences in standards of care expected from contracted provider programs versus state operated programming.[7] Some Regional Center staff feel that the current MRDD Quality Assurance (QA) system may be inefficient and/or time consuming, while some providers view it as intrusive and ineffective. MRDD's internal processes were also cited as an area of larger concern.[8] The Missouri DMH visions for 2007-2012 include establishing new approaches to quality assurance and highlight regional center reform.[9]

What Missourians with DD and Their Families Are Saying[4]

Statewide Needs Assessment Results:

- **Generally speaking, 20% of people surveyed reported awareness of some type of abuse/neglect of persons with disabilities in their community, either physical, sexual, financial, or human/legal rights violation.**
- **59% of respondents felt that people with disabilities were *very safe* or *mostly safe* in their community.**
- **However, 41% felt that people with disabilities were only *somewhat safe* or *not safe at all* in their community.**

Challenges in quality assurance for community inclusion:

- **People with disabilities were most often felt to be included in community life through 1) support and involvement of community organizations and businesses, and 2) through attitudes of acceptance from within the community.**
- **However, barriers of attitude and lack of understanding were also often stated as important factors in why people with disabilities are excluded from community life.**
- **Many people felt that persons with DD and their family members are included in planning that affects their lives. Family and friends most often supported them to participate in the planning process.**

Quality assurance for decision-making regarding community inclusion involves effective person-centered planning. Indeed, the MPC has recommended that any movement of individuals from habilitation centers must be done from a person-centered approach by allowing the planning process to be directed by the individual with assistance as needed from a representative.[10] Yet, Regional Center workers statewide report perceiving a move away from person-centered care and toward mere compliance with health and safety directives, as opposed to finding a balance between the two.[11]

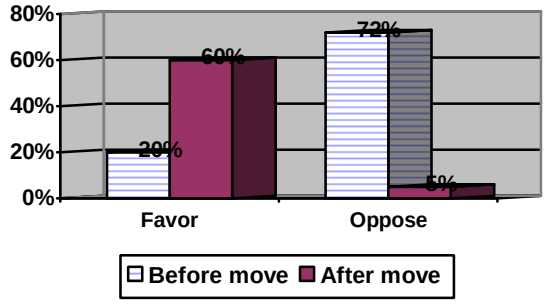
Abuse and Neglect Prevention. Between 2000-2005, at least 23 deaths linked to abuse and neglect at privately run homes and state-run centers under DMH's watch were reported in Missouri.[12] The 2006 Mental Health Task Force examined records of abuse and neglect from July 2005-June 2006. While the needs of residents and amount of services they received varied, data showed that residents of state-operated facilities were abused and neglected at a greater frequency (14%) than persons in community-based settings (5%).[13] Studies in other states have also found decreased allegations of abuse after community placement.[14]

Although abuse and neglect have been recently publicized in Missouri, parents of the residents show concern regarding the potential closure of habilitation centers, and possible impacts on their loved ones safety. Similarly, a large majority of the parents of residents of the Pennhurst Institution in Pennsylvania did not wish to relocate their children into the community. Nevertheless, following the move, families shifted to a strong support of community placement, as depicted in the chart below, and noted that their loved ones seemed happier living in the community.[15]

"I have my own home, but I have problems hiring help. There is little availability of help…they're not dependable. Maybe will work one month and then leave".

"Thinking about my child's future, the caregivers are on a low pay scale, and I'm worried they will be unreliable. The job is hard, and their skill level should be higher".[20]

Shifts in Pennhurst Parent Opinions Before and After Community Living Experiences



Direct Service Providers (DSP)-Lack of a Quality Workforce. An important barrier to making personal choice a reality for people with disabilities is the lack of a stable direct care workforce. A study by DMH in 2002 estimated the annual turnover rate of DSPs to be 68%.[16] Lack of DSPs has been primarily attributed to low wages and poor benefits. Studies indicate a decrease in staff turnover rate with increased rate of pay.[17] Decreases in turnover were found when persons with DD in the Missouri Independence Plus Pilot program were given control over their funds and could choose to increase wages.[18]

Participation in the Voting Process. Today, in most democracies, the right to vote is granted as a birth right without any qualifying test. The MPC works to increase participation of Missourians with developmental disabilities in the voting process through the encouragement of people with DD to register to vote, obtain voter identification, serve as an election judge, or call voters.[19]

What We Recommend

These recommendations are offered to supplement that which was already stated within recent reports on abuse and neglect.

- Promote efforts to support individuals and families in receiving services which will allow them to provide care for their family members in their home or a community setting of their choice.
- Develop options to include acute and emergency services including a community crisis response system for individuals in crisis and to prevent more restrictive placements.
- Promote efforts to increase flexible funding systems that allow dollars to truly follow the individuals to the community and in the community.
- Increase early access to services prior to individuals reaching a crisis point and potentially reducing the need for more costly services.
- Provide critical supports for direct care staff including training, credentialing, and adequate pay to ensure safe, quality supports for individuals receiving services.
- Support efforts to fund and expand the College of Direct Support as an excellent vehicle for providing better supports for direct care staff.
- Promote quality of life as an essential component of safety and advocate to prevent safety from becoming a means to limit an individual's right to choose a life in the community.

SAFETY AND QUALITY ASSURANCE ENDNOTES

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TRANSPORTATION

"Access to transportation is often a powerful positive predictor not only of employment, but also of several other quality of life indicators such as political participation, access to entertainment, socializing, and religious attendance. Likewise, inaccessible transportation limits the ability of people with disabilities to participate in these activities."[1]

Our Beliefs

The Missouri Planning Council for Developmental Disabilities (MPC) believes that persons with developmental disabilities (DD) should be able to have transportation that is available and meets their needs.[2] Without accessible transportation, persons with DD may not be fully included in the community.

MPC Beliefs

- **Community inclusion is the basis of the services and supports that people receive.**
- **Services and supports provide opportunities for people with DD to be valued members of the community, making contributions as well as receiving needed supports.**
- **The system promotes the use of community resources, and in so doing, builds community capacity.**
- **Services and supports are accessible and easy to use.**

MPC's Statewide Needs Assessment findings indicate that Missourians with DD still struggle with the availability and cost of accessible transportation that allows them to go where they need to go, when they need to go.[3] Individuals indicate that transportation challenges prevent them from working and increasing their independence through increased income. Many others indicate that transportation prevents them from enjoying social and recreational activities. This especially affects. Missouri's many rural communities, thus promoting isolation and lack of integration in the community. When participants were asked what could be done to improve the community for persons with disabilities, one of the top three comments was to improve transportation, further validating the importance of this issue to persons with disabilities and their families.

What the Research Says

While transportation services for persons without disabilities have improved, the gap for persons with disabilities has actually increased in recent years according to the National Organization on Disability.[4]

A national study by the U.S. Bureau of Transportation Statistics (2002) discovered six million people with disabilities have difficulty finding needed transportation.[5] Further, over a half million people with disabilities do not leave their homes due to transportation difficulties, impacting participation in work, social activities, worship, and other activities.[6] Nationwide, one third of people with disabilities have problems with inadequate transportation, as compared to one tenth of people without disabilities.[7] Meanwhile, the inequity of funding for highways versus public transportation appears to indirectly discriminate against these persons.

Systemic Change in Coordination. A report by the National Council on Disability (NCD) states that real change in transportation will not occur until funding is provided for comprehensive, accessible public transportation.[8] Previously, the "2003 National Dialogue, Transportation Policy and Research Forum on Accessible Community Transportation in America"[9] outlined seven areas for national improvement with corresponding action plans.

1. **Unified Public Transportation Systems**
2. **Systems for Effective Customer Feedback**
3. **Coordination for Rural Transportation**
4. **Transportation Training for Youth**
5. **Improvement in use of Mobility Aids**
6. **Travel Training Programs**
7. **Improvement in Best Value ADA Paratransit**

What Missourians with DD and Their Families Are Saying[10]

How People Get Around

Respondents thought persons with DD were *most likely* to use:
- **(47%) public transportation**
- **(28%) rides from family/friends**

Respondents thought persons with DD were *least likely* to use:
- **(39%) special transportation**
- **(37%) self-transportation**

Adequacy of Transportation Options

When averaged, no option achieved a rating of more than *fair*.
- **(72%) community-based transportation rated inadequate/fair**
- **(69%) special transportation rated inadequate/fair**
- **(62%) public transportation rated inadequate/fair**

Top 5 Challenges in transportation:
- **Availability, especially in rural areas**
- **Cost to meet transportation needs**
- **Limited transportation schedules**
- **Reliable, consistent transportation services**
- **Vehicle accessibility**

"Transportation that was offered to my 4 year old was a Vo-Tech bus and that had high school kids on it."

"You can't be spontaneous because it is so hard to set up transportation—it takes too many calls and too much red tape to get something arranged."

"There are no buses with wheelchair lifts."

Rural Transportation. The passage of the Federal Public Transportation Act of 2005: "Safe, Accountable, Flexible, and Efficient Transportation Equity Act (SAFETEA-LU)" will assist in providing resources for accessible transportation in rural America.[11] Although this addresses a need for transportation to medical appointments and employment opportunities, transportation for recreational and social opportunities are lacking.

Emergency Preparedness. Recent experiences with natural disasters in this country have raised public awareness of the need to plan for evacuation of persons with disabilities in the case of such events. In a recent testimony before the U.S. Senate Special Committee on Aging,[12] an official stated the challenges of identifying "transportation-disadvantaged populations," determining their needs, and providing coordination for their transportation. It appears state and local emergency management officials across the country show wide variation in their attempts to address these special issues.

"Don't have a taxi service and OATS is usually booked with appointments for senior services."

"They sometimes forget me. It does cause trouble with work. Weekends are my biggest problem."

"For an accessible bus, you have to schedule two weeks in advance. If you miss, you still have to pay."[13]

The State of the State in Transportation

According to the Community Transportation Association of America (CTAA), in 2005, Missouri had a "comprehensive" approach to transportation involving many agencies, organizations, officials, and disadvantaged populations in statewide coordination efforts.[14] They did, however, find inactivity in the Missouri legislative committees on special transportation needs, which were then officially eliminated in 2006.

In 2005, the Missouri Department of Transportation (MODOT) began the Missouri Advance Planning Project (MAP) and produced a summary of the "Trends and Conditions".[15] MODOT reported the following critical trends in Missouri:

- Missouri's population is aging
- Demands on the transportation system are increasing.
- Missouri's transportation infrastructure is aging and will require significant investment.
- Although the state's transportation funding outlook is improving, instability remains as costs increase.
- Land use and development decisions in the state place greater stress on the transportation system.
- There are few long-range, multimodal, multi-jurisdictional views of transportation.

While MAP poll respondents generally expressed support for placing much more emphasis on transportation that would benefit economic development, only mild support was noted for increasing emphasis on accessibility and availability of public transportation.

What We Recommend

These recommendations are suggested to increase access and availability of transportation to meet the needs of Missourians with disabilities.

- Encourage Missouri Department of Transportation to plan for and carry out projects that increase the availability of public supported transportation and increase public awareness of transit issues for people with developmental disabilities.
- Enhance coordination of transportation options in the State by creating an infrastructure that will facilitate the efforts of Private and Governmental transportation providers to more effectively and efficiently use available transportation resources.
- Increase the level of funding by the Missouri Legislature for affordable accessible and flexible transportation, especially in rural areas.
- Develop transportation plans that will address the emergency evacuation of person with disabilities in the event of a natural disaster or other type of catastrophic event. Encourage local communities to participate and engage individuals with disabilities and family members in developing local plans.

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